

ANNUAL REPORT

2024-2025



**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING





Chair's Report

It is amazing to think that this year, 2025, is the 40th anniversary of our charity. Founded in 1985 as the Jennifer Trust and merging with the SMA Trust in 2018, SMA UK is the leading charity in the UK for the SMA community. We have achieved so much during these last 40 years and will continue to be here for all those affected by SMA into the future.

2024/25 was another busy and demanding year for our incredible team and I'm extremely proud to look back at the successes and achievements that we have had over the last 12 months.

In line with our strategy, 'Building a Future Together', supporting anyone living with SMA remains at the core of what we do. Our exceptional Support Team continue to be the backbone of the charity providing information, practical, and emotional support to countless families across the UK. In October, in partnership with Rareminds, SMA UK launched a free confidential counselling service to support anyone affected by SMA.

Turning to advocacy, we continue to campaign for SMA to be added to the Newborn Screening Programme and advocating for NHS funding for both Nusinersen and Risdiplam to continue through consultations leading to their review in being postponed to late 2025. This has allowed the team to gather more information from the community on how positively treatment can affect the outcomes of people living with SMA. Furthermore, after several years of planning, in July 2024, we formally launched the SMA Care UK project working in partnership with John Walton Muscular Dystrophy Research Centre and Newcastle University.

With the website and social media platforms providing regular, up to date and informative PIF accredited information, our community is in the best position to make informed choices and to feel connected with other members of the SMA community.

The finances of the charity remain strong despite the pressures faced by the UK charity sector. This is down to you, our incredible and generous supporters as well as our amazing fundraising team. 2024 was our most successful fund raising year ever with so many fantastic fundraiser events and grants from trusts and foundations.

We received our second year of funding from The Motability Foundation enabling us to deliver the SMARt grants. We also secured a legacy payment from the Edward Gosling Foundation which will help us well into the future.

Four of our trustees ended their terms in office and I would like to say a special thanks to Julian Fiorentini, Michael Collins, Toby Mildon and Ros Quinlivan for their time and expertise whilst serving on the Board. In November we welcomed two new trustees, Hassan Sobati and Dan Worrall and we are excited to have them as part of our Board.

I'd like to thank my fellow trustees for all the time they give as part of the Board and as part of the charity. I would also like to recognise and thank all of my colleagues at the charity who work so tirelessly to ensure that SMA UK delivers for our community.

We are in a strong position but it is important we don't become complacent. There are many headwinds in the world at the moment and we must remain vigilant to the impacts on the economy, society, and our charity.

Mark Dearlove
Chair of the Board of Trustees



CEO's Report

As we approach SMA UK's 40th year as a charity, I am so proud to look back on 2024/25, particularly the work the SMA UK team have done on behalf of the SMA community.

In July 2024, after months of consultation, we successfully launched our new 4-year strategy: Building a Future Together (2024- 2028). The strategy aims to build on our strong foundations, experiences and expertise to ensure we deliver the best outcomes for the SMA community and make sure that supporting anyone affected by SMA is at the core of everything we do.

Some of the most recent highlights include the changes we made under our Flexi Grant programme as well as introducing a new free counselling service for those affected by SMA.

I can't thank our incredible supporters and donors enough for all their endeavors over the last 12 months, from sky dives, marathons and other challenges. Without your willingness to go above and beyond, we wouldn't be able to carry out our vital work.



A stylized white signature of Giles Lomax on a blue background.

Giles Lomax
Chief Executive Officer

SMA UK CEO Giles Lomax with his family.
His six year old twins, Zara and Finn are living with SMA,
and are the inspiration behind his work with the charity.



ADVOCACY

UPDATE





SMA REACH Steering Committee updates

Portia Thorman (Head of Advocacy and Community) continues to represent SMA UK within the REACH (Research and Clinical Hub) UK Steering Committee.

The SMA REACH UK hub is a strong national network of expert clinicians that supports research and clinical care for people with SMA. It helps develop and improve ways to measure how well treatments work – making sure these measures are useful for both patients and clinical trials. As well as discussing current and evolving issues in the SMA field, the steering committee also review applications to access clinical data for research purposes.

Throughout the year, Portia has been sharing the views of the UK SMA community, gathered through collaboration with SMA UK's support team, WhatsApp groups, surveys and in-person community events to help ensure that research focuses on the real needs and priorities of people living with SMA.



Adults' perspective workshops and report

We hosted two insightful workshops in Manchester (17th January 2025) and London (28th February 2025), bringing adults living with SMA and specialist clinicians together to discover adults' perspectives of clinical care across the UK.

The outcome, the "Adults Perspectives Report", focuses on the experiences, priorities, and recommendations for adults living with SMA in the UK. It highlights the challenges faced in transitioning from paediatric to adult care, the gaps in clinical and social care, and the need for improved standards of care (SoC) tailored to adults. It was concluded that a single, comprehensive Standards of Care for adults document is needed to guide best practice, reduce inequities, and support funding for Multidisciplinary Team clinics.

It should reflect the social model of disability, focus on individual needs, and promote collaboration between health and social care teams.

Iryna Bernyk who attended the workshop said: 'As an adult living with SMA, the workshop was truly special for me. It was a fantastic opportunity to not only share my own journey as an adult living with SMA, but, just as importantly, to meet and connect with such an inspiring group of people.

The sense of community, shared determination, and the drive to make a difference were so uplifting. It's moments like these that remind me how powerful it is to be part of this network – not just fighting together, but also learning from each other, supporting one another, and pushing for meaningful change.

I left feeling more connected, more hopeful, and incredibly grateful for being part of such a strong, supportive network."

Newborn Screening



UK Newborn Screening Committee (NSC) Progress towards an In-Service Evaluation (ISE)

In February 2025, the UK National Screening Committee (NSC) published an update on the In-Service Evaluation (ISE) for SMA newborn screening. The ISE, similar to a pilot, will screen a percentage of UK newborns over a set period to generate UK-specific evidence. It will inform a final decision on whether SMA should be added to the national newborn screening programme.

To support the ISE delivery, the NSC has established sub-groups focused on laboratories, data and methodology and the clinical pathway. This includes developing parent/professional information. SMA UK is contributing to several of these groups, bringing in vital patient experience.

Delays and Advocacy

Despite planning progress and the commitment of all those involved in the Partnership Board, at the time of writing there was still no confirmed start date for the ISE. We understand the delays have been largely due to the Government's spending review.

SMA UK, alongside Muscular Dystrophy UK, the SMA REACH UK network, and the Newborn Screening Alliance, is actively pushing for progress. We've written to politicians, engaged with the NSC, and raised awareness through meetings, petitions, articles, and public speaking. We're also working with the Scottish government to help prevent inequality in access across the UK.

The Lancet Letter

On 7th February 2025, The Lancet published a powerful letter from leading SMA clinicians, highlighting the stark differences in outcomes between babies born with SMA in the UK and those in countries with newborn screening. The letter shares harrowing statistics, showing that while UK babies treated after symptom onset often face severe disability or death, children in countries like Belgium, treated pre-symptomatically, are thriving.

We urged the SMA community to share this letter and contact their MPs to demand faster action. SMA UK remains committed to securing SMA newborn screening for every baby born in the UK.



ENMC Workshop

The ENMC Workshop SMN-related neurodevelopmental disorder: type 1 Spinal Muscular Atrophy and the brain was held from 31st January – 2nd February 2025.

Portia Thorman, brought the patient perspective to this international expert workshop. It was highlighted that some children with SMA Type 1, who are now living longer thanks to new treatments, may experience developmental challenges such as speech delays, learning difficulties, or behavioral differences.

It was agreed at the workshop that early monitoring, timely therapy (especially speech therapy), and strong family support can make a big difference. Families should be encouraged to share concerns with healthcare providers, who can track development over time and tailor support.

Experts are now working together internationally to:

- Launch a global survey on developmental challenges in SMA
- Develop better care and diagnostic guidelines
- Involve families in shaping future research and support systems

These efforts aim to ensure every child with SMA gets the care and opportunities they deserve.

NICE Multi Technology Assessment (MTA) of Risdiplam and Spinraza

On 19th April 2024, SMA UK, in collaboration with other patient organisations and in consultation with NICE, led a joint response to the External Assessment Group (EAG)'s report evaluating the clinical and economic evidence for Spinraza and Risdiplam.

We submitted our response in September 2024. NICE acknowledged the concerns raised by SMA UK, partner organisations, clinicians, and pharmaceutical companies, including that the EAG report:

- Did not give equal weight to real-world evidence compared to clinical trials.
- Focused narrowly on mobility outcomes, overlooking SMA's broader impact on daily life.
- Did not account for the inherent limitations in trial size and duration in rare diseases like SMA, highlighting the importance of ongoing real-world data collection.
- Overlooked the need for individualised treatment options.
- Failed to value disease stabilisation as a major positive outcome.
- Relied on quality-of-life measures that are too limited to reflect the full benefits of treatment.

In December 2024, NICE postponed its committee meeting on the clinical and cost effectiveness of the drugs and commissioned a new EAG report to build on the original.



Partnerships

SMA UK worked with a number of our partner organisations including Scope, the Disabled Childrens Partnership and Genetic Alliance throughout 2024 on a wide range of campaigns, raising awareness of key issues such as rights on transport, inclusion in education and the need for faster diagnosis.

In December 2024, SMA UK joined the Wheelchair Alliance, an organisation that represents the voices of wheelchair users. We will work with them in calls for a more integrated approach to wheelchair provision and greater prioritisation of wheelchair services in the NHS.



SMA Care UK is a 3-year project established by clinicians and patient groups to update and implement UK Standards of Care for people of all ages living with SMA.

The current Standards of Care for SMA were written before disease-modifying treatments began to emerge and were published in two articles in 2017. A Family Friendly Guide was published in the following year. They covered a wide range of topics such as nutrition and bone health through to respiratory care. The new updated standards (SMA Care UK) will reflect how developments around treatments have changed the care and management needs of people of all ages living with SMA.

Its goal is for this care to be accessible to all who have SMA, wherever they live and whichever hospital they attend. People living with SMA are central to this work. Given the wide-ranging impact of SMA, there are many areas of care to consider. Respiratory, hip, spine, and transition to adult services will be the first topics to be reviewed.

In July 2024, Vanessa Christie-Brown was appointed as the SMA Care UK Project Manager and will be working in partnership with John Walton Muscular Dystrophy Research Centre, Newcastle University. . Vanessa will be working with a team of healthcare professionals and patient representatives to bring the project to fruition.



Partners and funders

We are extremely grateful to our funders who are supporting this project. Biogen, Roche and SMA UK have all committed funding towards SMA Care UK.

Partners:



Funders:



INFORMATION

UPDATE



PIF Tick Information Guides

Our twenty-seven information guides about SMA and related care, treatment and management topics are all available on our website. We send out printed copies when asked to do so.

Each guide is reviewed by experts and readers interested in the topic. This review is an important part of our information production system which we follow when we produce these guides.

The system supports our aim of producing accurate, evidence-based, up to date and accessible information. It was again accredited by the Patient Information Forum (PIF) this year.

All these guides carry the PIF Tick.
The top four during this report period were:

Looking After Your Child SMA Type 1

Page Views 3,002
Active Users 2,144

Adult Onset SMA Diagnosis and Care

Page Views 1,464
Active Users 1,179

Symptoms and effects of 5q SMA

Page Views 1,463
Active Users 1,041

The Genetics of 5qSMA

Page Views 1,602
Active Users 1,178



We continue to produce many other pages following similar principles. These include information about research and treatments with the top three areas in this section as follows:

Page	Page Views	Active Users
Zolgensma / Onasemnogene Abeparvovec	2,008	1,524
Spinraza/ Nusinersen	1,472	928
Evrysdi / Risdiplam	1,319	1,025

Our website pages about day-to-day living with SMA cover a wide range of topics from nursery and school to travel, sport, equipment and adaptations, financial benefits and many more. Each section focuses on topics of relevance to the age group and were accessed as follows:

Page	Page Views	Active Users
Adults	3,832	1,113
Teenagers	3,152	897
Children	1,840	1,014

“

‘The support & information section was very helpful when we first received the diagnosis, looking further into that section, the looking after your child with SMA 1 helped to understand the treatment options, how SMA 1 affects the different areas of the body and also the information about the allowances we may be able to receive, I have already ordered a Disabled Living Allowance form.’ – Parent



Webinars

When members of the SMA community raise questions that need expert answers that we don't have, we do what we can to find them. When possible, this results in a webinar hosted by a community member.

This year we were asked many questions about different types of diet. We were fortunate to find two experts willing to share their knowledge across three webinars that were released in February 2025. At the time of writing, they had been viewed a total of 148 times. There have been other topics where we have not had such success with finding an expert, but we haven't given up and will keep looking.

We hope the range of information we offer continues to respond to the needs of people new to and living with the condition.

SUPPORT

SERVICES

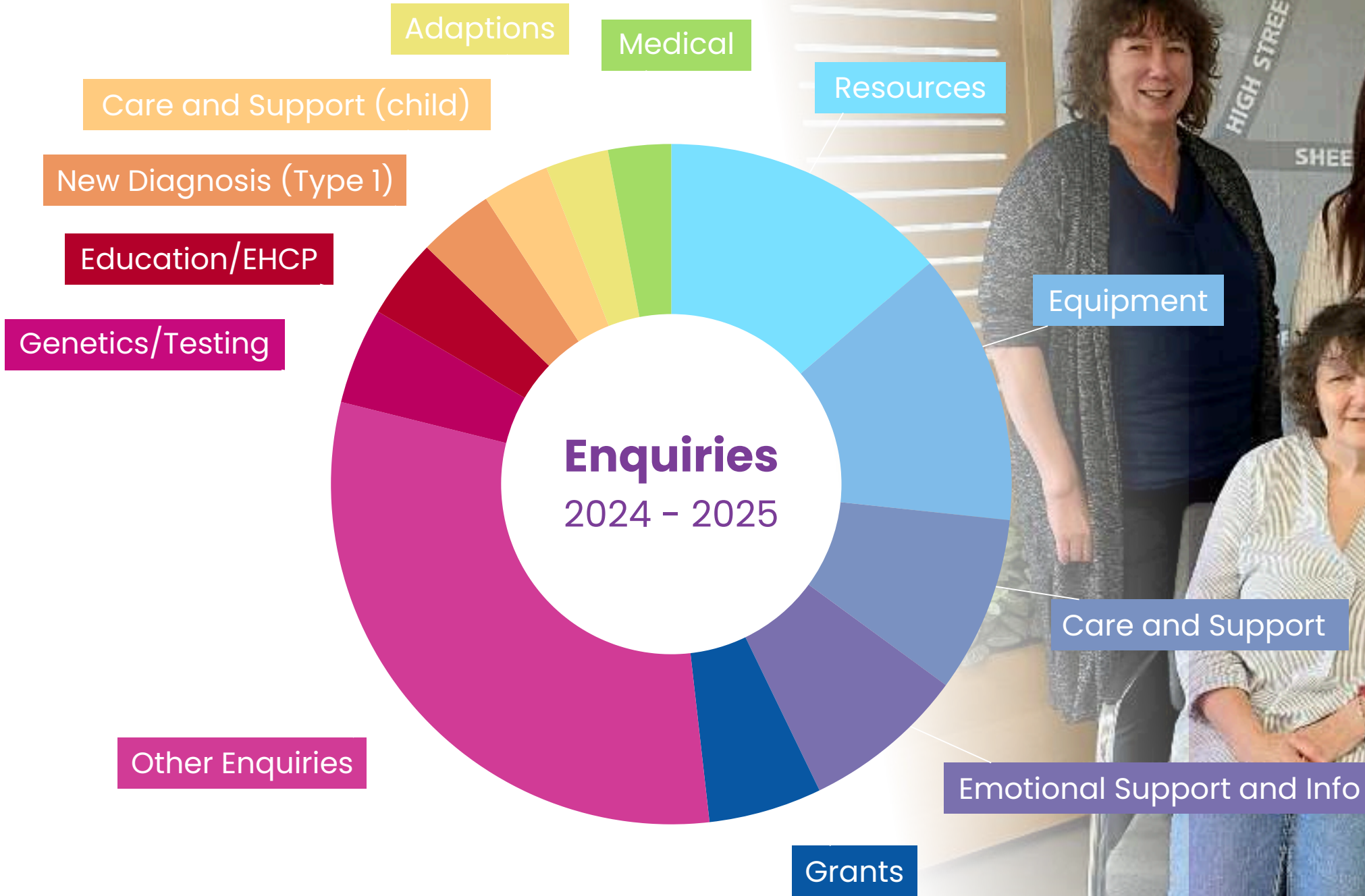
UPDATE



Supporting members of the SMA Community remains at the core of everything we do at SMA UK.

This year our Support Team have provided high quality advice, information and practical and emotional support to 492 families and individuals across the whole of the UK.

The chart to the right shows our top ten enquiries. Other enquires for support where in the following areas; Newley Diagnosed, Counselling, Financial benefits, Treatments, Housing, Social Connections, Supporting Letters, Legal Support, Orthotics, Vehicles, Travel, Bereavement, Transition, Advocacy, Clinical care and support crisis, Car seat, CHC, Hydrotherapy, Insurance, Mental health, Mobility, Newborn screening, Nutrition, Home visit request, Safeguarding, Sibling support and transport.



The support provided by the SMA UK Support Team has been incredibly important to me. I received a significant reduction in my care budget which severely impacted my independence and quality of life.

As soon as I reached out to the Team about this, they demonstrated their dedication to providing me with support – meeting with me on numerous occasions, giving me very useful advice, carefully writing supporting letters, guiding me through the process.

This made an enormous difference in helping me through this difficult time and resulted in a re-assessment being performed for my care needs. I am really grateful for their commitment and continued support.

The support team have also responded to 93 enquires from healthcare professionals:

25 enquiries	2 enquiries
Resources	Care and Support (Child)
12 enquiries	Emotional Support
FCG	Legal
11 enquiries	Medical
Housing	New Diagnosis (type 2)
9 enquiries	Supporting letter
New Diagnosis (type 1)	1 enquiry
8 enquiries	CHC
Care and Support (Adult)	Equipment
5 enquiries	FCG2
Car Seat	Grants
3 enquiries	Mailing/first contact
Education	New family/contact with others (LED)
	Ongoing support
	SMA – SMARD

Transition Workshop

We understand that there are many questions and complexities that arise when a young person is transitioning into adulthood. Therefore, we were delighted to be able to welcome thirteen young people aged 13 – 18 years and their eighteen family members and their carers to this interactive day of free workshops in April 2024.

Hosted by our Support Team and five young adult volunteers at the Midlands Arts Centre, the event was attended by our guest speakers who led sessions that explored a wide range of topics.

Speakers covered key transition topics including the T-KASH framework (Marie McGee), accessing adult health and social care (Jane O'Connor & Lisa Cutsey), housing options (David Abbey), managing PAs at university (Tim & Christopher Pool), university support (Kate Waugh, Birmingham University), driving and transport adaptations (Dominic Hibbin & Becky Brown, RDAC), the Duke of Edinburgh Award (Sarah Lalieu & Matthew Lanham), and accessible travel (Cheryl Everitt).



Attendee feedback:

"Huge thank you to @sma_uk for a great day, and for introducing us to people and opportunities we'd never dream of"



SMART Moves

Our SMARTMoves grant ran for the second year thanks to The Motability Foundation. This grant has enabled us to support more people living with SMA in purchasing wheelchairs and wheelchair adaptations.

From 1st April 2024 – 31st March 2025 we supported 65 children and adults with new wheelchairs and adaptations.

By working alongside other grant giving charities, we have supported adults to secure funds to purchase new powered wheelchairs.

We have also enabled families to access their child's first manual or powered chair.

The grant scheme is split into three sections:



SMART Moves 1.1

Offering grants to fully fund powered wheelchairs and manual wheelchairs that cost up to a maximum of £5,000.



SMART Moves 1.2

Offering grants of £5,000 towards powered wheelchairs and manual wheelchairs that cost over £5,000.



SMART Moves 2

Offering grants up to £2,500 for other mobility equipment, including risers, batteries etc.



FlexiGrant programme

In July 2024 we relaunched our FlexiGrant program to the SMA Community. There are two grants:

FlexiGrant 1: A maximum grant of £500 to help with the costs of accessing NHS funded treatment or assessment e.g. travel costs.

FlexiGrant 2: A maximum grant of £600 to assist with buying items that support independence and alleviate hardship.

From the 1st April 2024 – 31st March 2025, we supported 128 people with these grants totalling £40,401.18

Family feedback:

"Thank you so much for the award of this grant. It is greatly appreciated, and we are blown away by the quick turnaround and generosity of SMA UK!"

"Thank you very much to the SMA UK staff for all your help and support, not just with these grants but on the whole. This charity supports the community so well and without the Support Team I'm not sure where my family would be."



Toy Packs

Our multisensory toy packs are sent free of charge to families with babies aged up to 12 months old who have a SMA diagnosis. The items in our packs will entertain during the day, add fun at bath time, and provide comfort at bedtime. They provide visual, tactile and auditory stimulation. 26 toy packs were sent this year and have been well received.

Family feedback:

"I never expected such a lovely toy box- a huge amount of toys and a lovely box it is delivered in and felt I had to call to thank the charityyou are all AMAZING!!"

"The toys arrived this morning, thanks so much! It's a really lovely box and super generous of the charity to provide all these toys."

Partner Organisations

The Support Team continues to visit and link with Neuromuscular Centres, meeting Neuromuscular advisers and specialist nurses. They work closely with other charities/organisations to provide information, and resources that bring the best possible support to the the SMA Community.

Rareminds Counselling Service

In October 2024, we launched a new pilot counselling service for all those affected by SMA.

Working in partnership with Rareminds, a specialist, nonprofit, rare disease counselling and psychotherapy service, we have been allocated two SMA counsellors offering six to twelve sessions to individuals or couples affected by SMA.

Our dedicated Rareminds counsellors provide a safe, confidential relationship where you can explore difficult thoughts or feelings and consider new ways of working through your difficulties.

During the pilot a total of 14 individuals accessed the service, 10 who have SMA, 3 parents and 1 partner, with 101 counselling sessions provided. Following a full review of the pilot we are continuing to work in partnership with Rareminds to provide this service.

"I found the sessions so helpful. I have had support in the past but never felt they understood / I could talk about my disability and I got exactly what I needed from the sessions. I was supported through ongoing as well as current issues and feel in a much better place now going forward being able to manage challenges. I am very grateful and would highly recommend to others" – Client

COMMUNITY

ENGAGEMENT

UPDATE



SMA UK Ambassadors

In September 2024 we welcomed two volunteer Charity Ambassadors on board! Molly Everitt and Sanah Rauf are working with SMA UK to help spread awareness about SMA and support the important work we do.



Hi, I'm Molly – one of SMA UK's first Ambassadors! I'm 21 and studying Law with Criminology at the University of Liverpool.

Diagnosed with SMA Type 3 as a toddler, I've been connected with SMA UK ever since, and they've supported me and my family in countless ways.

Thanks to their SMARt Moves grant, I now have a life-changing wheelchair that's boosted my independence.

I'm passionate about raising awareness around accessibility, especially in music venues, and I'm so proud to support a charity that means so much to me. I'm excited to see where this Ambassador role takes me!

Hi, I'm Sanah Rauf – a 27-year-old artist, content creator, and proud SMA UK Ambassador!

I have SMA Type 2 and use my platforms on Instagram and TikTok to share my journey, raise awareness, and inspire others.



With a background in Film and TV, I now run art workshops, speak at events, and create content that promotes self-belief and resilience.

Living with SMA has taught me that mental strength matters most, and I'm passionate about helping others with SMA feel fearless and empowered.



Thank you to everyone who came and enjoyed our Picnic in the Parks in 2024!

We loved seeing so many old faces as well as welcoming so many new ones to these fantastic afternoons. We hosted six Picnics in the summer at venues in Yorkshire, Cardiff, Edinburgh, Birmingham, Essex and Belfast.

269 people (68 families) attended the events which brought together families and individuals living with SMA for an opportunity to network, share information and have fun!



It was lovely to meet up with people from last year, and new families too. It's so great to build those connections, and a support system so you don't feel so alone. – Attendee

RESONATE 2024



Resonate Adults

Over the weekend of the 26th –29th July 2024, 20 adults living with SMA and their carers attended our third Resonate weekend at the Calvert Trust, Exmoor.

The sun shone and the weekend was packed with fun activities such as kayaking, abseiling, bike riding, and archery! The weekend was an opportunity for attendees to meet new people as well as old friends and have fun in the outdoors!

For twins, Sam and Alex, this was the first holiday they had without family support. They said, "This is one of the first holidays with just PA's and they have been absolutely amazing it has been a big boost to our independence."



"All the experiences were amazing. The staff, the activities, the accommodation and the food."

"Such an amazing weekend and so lovely to catch up with old friends and meet new ones! An absolute highlight of the year! Being able to catch up with some of my closest friends is great as it's hard for us all to meet up as a big group throughout the year and finding somewhere that meets all of our needs."

"Absolutely amazing time and really enjoyed all the activities and always meets my expectations."

*"It's just been a fantastic opportunity for us as a family. There are very few opportunities that we get to have as a family, but also with other families of children with similar conditions in wheelchairs where we can do activities that everybody else gets to enjoy all the time. Without SMA UK we would probably never have met these other families. It's so nice to see the children just whizzing around together, having fun!" – **Attendee and parent of child with SMA***



Resonate Kids

During the 3rd–16th September 2024 we hosted our first Resonate for children at the Calvert Trust in the Lake District! 15 young people and children living with SMA attended, along with their parent/carers, enjoying similar experiences and activities to the adult's weekend such as archery, swimming and abseiling.



Living with SMA Podcast

Our Living with SMA podcast is an opportunity for the SMA Community to share and discuss relevant topics about living with SMA and disability in general. Working closely with the community and key contributors, we produce regular podcasts that are shared across various digital platforms.

Six new episodes were released this year from “Getting ready for University” to “Motherhood, Parenting with SMA”

During this reporting period we there has been **789** podcast downloads

SMA UK WhatsApp Community Networks

Our Community WhatsApp groups continue to grow in numbers, offering a space to share knowledge and experiences as well as have general conversations with likeminded people.

Our adult groups have become much more active following the adult workshops in January and February 2025, with 10 new members joining the WhatsApp community as a result.

The Families Network has also been especially active, providing invaluable help and support to newly diagnosed members as they join the community.



The Adults WhatsApp group has added 16 new members this year, bringing the total to 40.



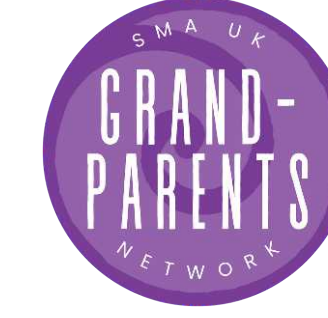
The Families WhatsApp group has added 36 new members this year, bringing the total to 110.



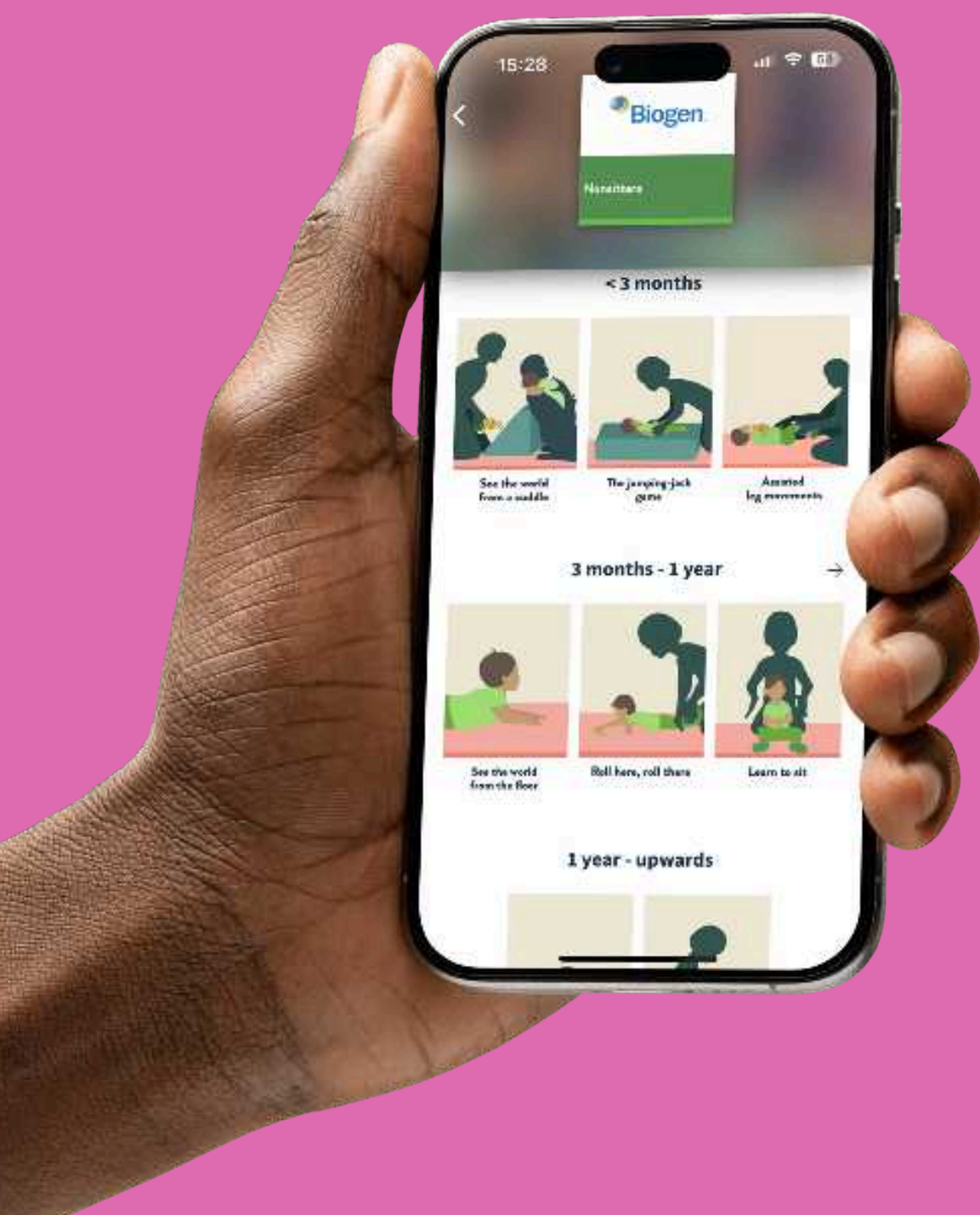
The Charisma Network (for teenagers) currently has 33 members. Recently, 8 members have transitioned to the Young Adults/Adults Network.



The Young Adults WhatsApp group has added 7 new members this year, bringing the total to 49.



NEW! The Grandparents WhatsApp group has added 26 new members this year, bringing the total to 26.



Biogen's new exercise app

Working alongside leading specialist physiotherapists we assisted Biogen in creating a new exercise app for people living with SMA.

The app is aimed at both children and adults and consists of exercises that can be done in the home environment. All exercises have been chosen based on level of function and age.

Read more about the app and download it at:
smauk.org.uk/izcz

FUNDRAISING

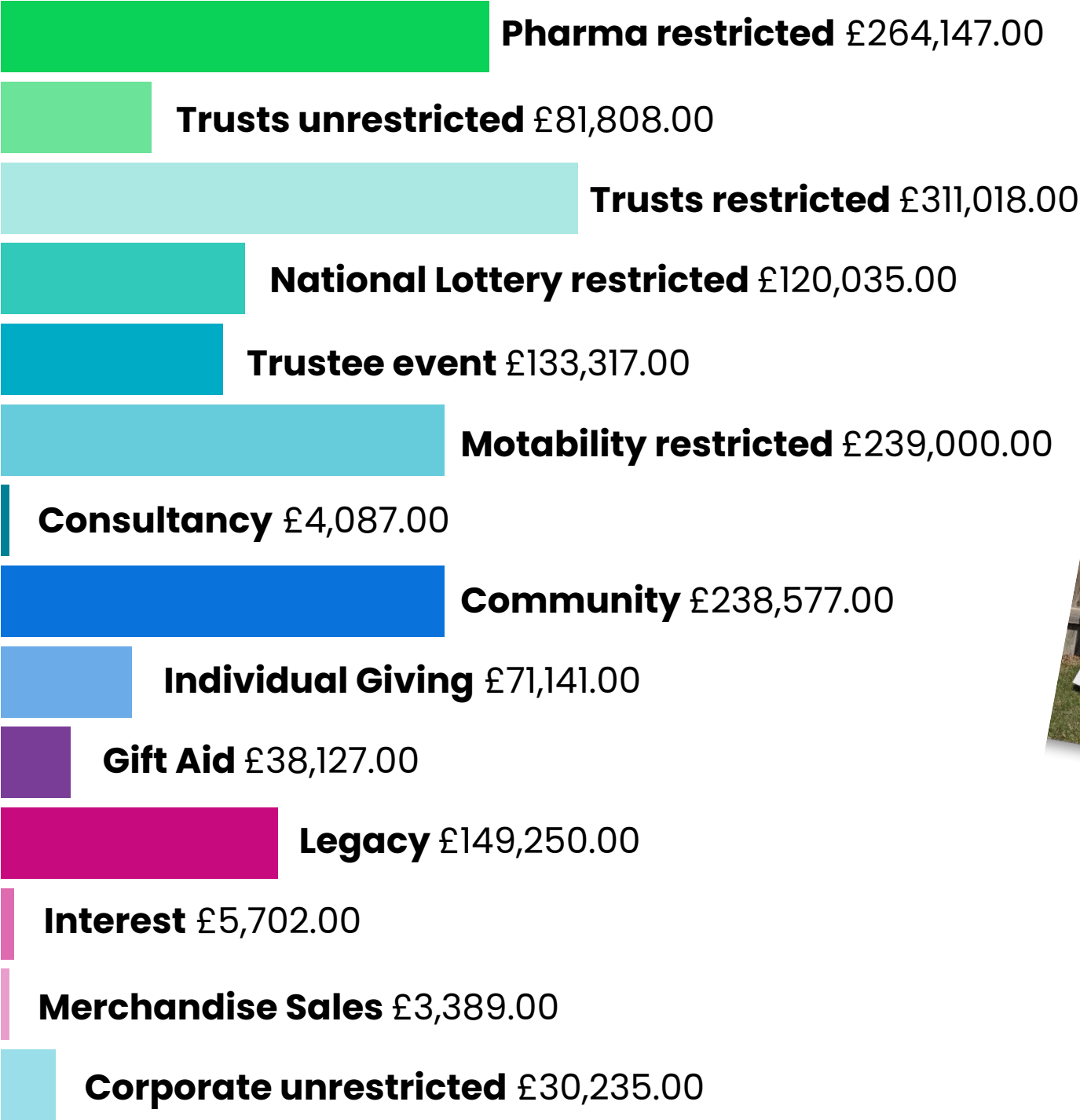
UPDATE



All of SMA UK’s achievements, whether it’s delivering vital support services, producing accessible information, or advocating for better care are only possible thanks to the incredible generosity of our donors and fundraisers. We are deeply and sincerely grateful for every individual, family, organisation, and foundation who chooses to support our mission. Their dedication enables us to continue our work and make a meaningful difference in the lives of those affected by Spinal Muscular Atrophy.

Looking ahead, it is crucial that we maintain a strong and sustainable foundation of financial support. In order to continue responding effectively to the evolving needs of the SMA Community, and to ensure that individuals and families living with SMA receive the help and resources they deserve, our fundraising income must remain both consistent and resilient. Ongoing support from donors and fundraisers is not just appreciated, it is essential to our ability to grow, adapt, and deliver lasting impact.

In 2024/25, through various fundraising activities, grants and donations our raised income was £1,616,553.



#KnowNoBounds campaign

The KnowNoBounds campaign was founded by Josh Wintersgill to raise awareness about the urgent need for greater accessibility outdoors for disabled people. Driven by a vision of inclusion and empowerment, the campaign also aimed to raise funds to purchase an all-terrain wheelchair that would be available for members of the SMA Community to use.

On 15th June 2024, Josh’s campaign partner, Maxwell McKnight, undertook an extraordinary challenge — climbing Mount Snowdon in an X8 off-road wheelchair. Supported by a dedicated and enthusiastic team, Maxwell completed the climb in an impressive 6.5 hours, demonstrating not only the power of determination but also the potential of inclusive technology.

We were thrilled to celebrate this incredible achievement at a launch event hosted in March 2025 at the Stelios Foundation, one of the generous donors to the campaign. During the event, we proudly unveiled the X8 off-road wheelchair, which will be made available for community hire in 2025, giving individuals with SMA the opportunity to explore and enjoy outdoor environments more freely and independently.

Our new X8 wheelchair has been called "Limitless" in honour and loving memory of Clare Gray, a Trustee for SMA UK and advocate for all those living with a disability.





SMA Awareness month 2024

We relaunched our SMA UK Teddy with a competition to name the bear. SMArty the Aware Bear was very popular, and we were delighted to see so many of the community sending in fantastic photos of SMArty being taken on travels across the world!

The Big Give

We were delighted to be selected to take part in the matched funding campaign The Big Give Christmas Challenge once again and we exceeded our fundraising target of £30,000. Our special thanks to those supporters who pledged to make up our 'matching pot' for making this possible.



Clay Shoot

In May 2024 a clay shoot was organised in partnership with the Game and Wildlife Conservation Trust. This was successful in raising £124,868 which was split between both charities, and we are extremely grateful to everyone who joined us for this event and who kindly donated auction prizes.

Individual Giving

We received monthly donations from 158 supporters this year and are grateful for their continuous support. We would also like to extend our heartfelt thanks to everyone who made donations in memory of loved ones over the past year.

These generous and meaningful contributions not only honour those who have passed, but also help us continue our vital work supporting individuals and families affected by SMA.

Furthermore, we are deeply grateful to those who chose to support our work by leaving a gift in their will. These lasting legacies make a profound difference, helping us plan for the future and continue providing vital support and services.



Community Events

We received incredible support from the community, who took part and arranged events all over the country to support SMA UK. The London Marathon and Great North Run continue to be popular events, and we have also seen fundraisers being creative with ideas from family fun days to Himalayan Treks!

Trusts and Foundations

We are forever grateful for the grants we receive from Foundations and Trusts. Both restricted and unrestricted funding ensure that we can continue to offer various workshops, outdoor activities and FlexiGrants to the SMA Community.



Registered with
**FUNDRAISING
REGULATOR**



Fundraising Story

Rachel Toth, from Dundee, took SMA UK to new heights by climbing the Himalayan peak Yalung Ri, which rises to an impressive 5,630 metres (18,471 feet).

At the summit, she tied a specially made SMA UK flag alongside Tibetan prayer flags, marking the highest point ever reached by one of our supporters.

Rachel was inspired to take on the challenge by her close friend Alistair, who has SMA Type 3 and is a Trustee of SMA UK.

Her incredible effort raised £3,000 to support the charity's work.

DIGITAL

COMMUNICATIONS

UPDATE



Social Media Highlights

This year, we continued using our social channels to raise awareness, share real stories, and support the SMA community. Our focus stayed on honest, accessible content, and we saw steady growth across all platforms.

Instagram was our fastest-growing channel with a 12.6% increase in followers, thanks to regular and engaging posts. Facebook remained our biggest community space, growing by 2.4%, while YouTube saw a 15.4% boost in subscribers as more people tuned into episodes of the “Living with SMA” Podcast and informative webinar videos. LinkedIn and X also grew, helping us stay visible in policy, research, and advocacy spaces.

Our most engaging content continued to be personal stories from families and individuals with SMA. Campaigns like SMA Awareness Month in August brought great cross-platform engagement, and we’re seeing the most impact when our community leads the conversation.

Looking ahead, we aim to focus more on short-form video, gathering video content from our upcoming community events. As well as sharing more information about the kind of support our Community Support Team can offer.

A huge thanks to everyone who shared, liked, and supported us on socials this year, your voices are at the heart of everything we do.



SMA Matters & e-newsletters

In 2024, we continued to keep our community informed and connected through regular updates. We published two editions of SMA Matters, our bi-annual magazine, in April and September. These magazines share a mix of news, community stories, research updates, expert advice, and helpful information to support people living with SMA and those around them.

In addition, we send out monthly e-newsletters. These allow us to stay in touch more often, providing quick updates about what’s happening in the SMA community, and plenty of opportunities for people to get involved with fundraising.

Digital Comms in numbers



402,279
Facebook Reach



48,453
X Impressions



110,611
Instagram Reach

3,889
SMA Matters
Subscribers

3,736
E-News
Subscribers




42,172
Youtube Views

1625.4
Youtube Watch
time (hours)

OPERATIONS

UPDATE





Strengthening Our Digital Infrastructure and Advancing Operational Efficiency
In response to the growing threat of cyber-attacks, we made the strategic decision to review our cybersecurity policies and strengthen our digital defenses. This initiative included a comprehensive upgrade of our firewall systems and antivirus software.

Our efforts culminated on 6 January 2025, when SMA UK achieved Cyber Essentials certification. This UK Government-backed scheme helps organisations protect themselves against the vast majority of common cyber threats. Organisations with Cyber Essentials controls in place make 92% fewer cyber insurance claims, demonstrating the scheme's real-world value.

This certification offers our community the assurance that SMA UK takes cybersecurity seriously and is actively working to keep their data safe. While no system can ever be entirely immune to attack, SMA UK is now better equipped than ever to mitigate cyber risks.

In line with our broader digital strategy, we've also completed a major upgrade of our e-commerce platform. Our shop is now integrated with Shopify, replacing the legacy system previously hosted at smauk.org.uk. Shopify is a global leader in e-commerce solutions for small to mid-sized organisations.



This move delivers both cost savings and enhanced functionality, while also ensuring full compliance with PCI DSS (Payment Card Industry Data Security Standard) offering greater security and peace of mind for those making purchases through our online store.

We have also continued to roll out our IT-for-Staff Strategy, launched last year. This multi-year programme focuses on modernising staff technology across the charity. We began by replacing the oldest laptop computers – some of which were too outdated to run supported versions of Microsoft Windows.

This phased refresh will continue over the next three years, allowing us to manage costs efficiently by spreading investment across multiple financial years.

To round off our progress this year, our IT & Operations team has made significant strides in automating key business processes. This year, we've implemented automation in the approval of Flexible Grants and the way we manage credit card expenditure across the organisation. These enhancements reduce manual effort, increase accuracy, and support our goal of operational excellence.



Staff Team

As of 1st April 2024 – 31st March 2025

Giles Lomax – CEO

Lucy de'Lemos – Head of Development and Comms

Rebecca Lewis – Fundraising Manager

Yvonne Wright – Fundraising Administrator

Stacey Shillingford – Trust Fundraising Officer

Bec Noy – Digital Communications Lead

Michele Phillips – Head of Support

Jo Spicer – Community Support Practitioner

Claire Holdcroft – Community Support Practitioner

Becci Howell – Community Support Practitioner

Nicola Beer – Community Support Practitioner

Ally Allen – Community Support Grants Officer

Portia Thorman – Head of Advocacy and Community

Liz Ryburn – Information Lead

Gary Edgecombe – Community Services Officer

Vanessa Christie-Brown – SMA Care UK Project Manager

Martin Penning – Operations Manager

Lorna Penning – Accounting Administration

Dr James Sleight – Scientific Research Correspondent

Luis Canto E Castro (last day 31st May 2024)

Libby Roper (last day 29th May 2024)



Our Trustees

Mark Dearlove – Chair of Trustees
Katherine Jackson – Treasurer

Anne Marie Childs
Srinivas Madipalli
Alistair Emslie Smith
Julian Fiorentini
(Resigned 24th June 2024)
Lauren West
Yvette Edwards
Michael Collins
(Resigned 31st December 2024)
Toby Mildon
(Resigned 25th March 2025)
Rosaline Quinlivan
(Resigned 28th Feb 2025)
Tracey Jane Bailey Burnley
Ben Williams
Maryann Aspinall
Jennie Sheehan
Ross Hovey
(Resigned 31st December 2024)
Dr Hassan Sobati
Daniel Worrall

With special thanks to :

**SMA
EUROPE**

**MUSCULAR
DYSTROPHY
UK** | OUR MUSCLES
MATTER



SMAREACH UK

ADULT
SMAREACH

UK SMA
PATIENT REGISTRY



**spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING



SMA_UK



sma_uk



Spinal Muscular Atrophy UK

Unit 9, Shottery Brook Office Park, Timothy's Bridge Road,
Stratford-Upon-Avon, Warwickshire, CV37 9NR
office@smauk.org.uk | 01789 267520

Registered Charity Number 1106815

01789 267 520
office@smauk.org.uk
smauk.org.uk



#ScreenTodayForSMA

spinal
Muscular
Atrophy uk
SUPPORTING - PROMOTING - EDUCATING

FINANCIAL REVIEW

2024- 2025

TREASURERS REPORT

for the Year Ended 31 March 2025

Income for the year was £1,624k an increase of 28% on the prior year. Revenue was driven primarily by donations from the community of £470k due to tremendous fundraising efforts. The charity also benefited from a large legacy endowment of £200k from the Edward Gosling Foundation and legacy income of £149k.

Significant grant income was received all of which is restricted funding: the second year grant of 239k from the Motability Foundation as part of a programme of wheelchair and mobility equipment support for people living with SMA as well as grants for SMA Care UK of £162k and working with SMA of £120k.

The total pharmaceutical funding received during the year was £264k the majority of which is restricted for SMA Care UK. Pharmaceutical funding was 16% of total income compared to 13% in the prior year. Specific donations received in 2024/5 were Roche £114k, Biogen £90k, Novartis £50k and Scholar Rock £10k. We are committed to transparency on pharmaceutical funding and ensure that we do not accept funding from any party if we feel it will place the charity under undue pressure to act in a way that does not support or compromises our charitable objectives or independence.

SMA UK's spending is broadly divided between information provision, support and research – our charitable purpose – and fundraising and governance. We aim to maximise spending on our core purpose and ensure that other costs are carefully monitored. This year, expenditure on our core purpose charitable activities increased by £335k or 52% due to increased expenditure on the projects Motability, SMA Care, Know no Bounds and community events all of which utilised restricted funding.

Expenditure on fundraising increased by £80k or 39% on prior year due largely to expenditure required to run revenue generating fundraising events.

Overall, there has been an increase in expenditure in the year of £422k or 45% due largely to the grant funded projects which are serving the SMA community. The proportion of SMA UK costs that were spent on its charitable purpose, our value or pence in the pound, was 72p with the majority of resources focused on the provision of support to the SMA community and research.

Our net income for 2024/25 was a surplus of £264k compared to £326k in the prior year. The majority of the 2024/5 surplus relates to restricted funds grants provided by Motability for the 3 year equipment programme, Pharmaceutical support for SMA Care and various community engagement projects. The surplus is therefore committed to services to be provided in 2025/6 and subsequent years. As a result, SMA UK has finished the year with a strong cash position of £1,196k, £660k of which is restricted. The charity is operating within its reserves policy and the board will continue to monitor activities and reserves very carefully.



A handwritten signature in dark ink, appearing to read 'KJ', written over a light blue horizontal line.

Katharine Jackson
Treasurer

REPORT OF THE TRUSTEES

For the Year Ended 31 March 2025

The trustees present their report with the financial statements of the charity for the year ended 31 March 2025.

The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

As stated in its Memorandum and Articles of Association, Spinal Muscular Atrophy UK is established for:

- The relief of people living with Spinal Muscular Atrophy and related medical conditions;
- The relief of persons who are in need after experiencing a bereavement or loss due to Spinal Muscular Atrophy; and
- The promotion of research into the causes and treatment of Spinal Muscular Atrophy.

Public benefit

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's General Guidance on Public Benefit when reviewing the Charity's aims and objectives and in planning future activities.

ACHIEVEMENT AND PERFORMANCE

A detailed overview of the charity achievement and performance can be found in the Annual report 2025.

Future plans

We will continue to: advocate for access to the new drug treatments, representing the views of the SMA Community to regulatory authorities and pharmaceutical companies; monitor the roll out of NHS programmes and pharmaceutical initiatives supporting individuals seeking access. We will continue to provide and further develop our information, outreach and support services and opportunities for people in the SMA Community to connect with each other. Our fundraising efforts will need to achieve income levels that will enable us to achieve our goals. We will continue to adapt our working practices to ensure they are safe for both the SMA Community and our staff and trustees.

FINANCIAL REVIEW

Financial position

See Treasurers Report from Katharine Jackson, Treasurer.

Investment policy

No investments are currently held by the Charity. The investment policy is reviewed annually.

Reserves policy

Restricted reserves will always be applied in accordance with the Trust/donor's award specification. Where there is no specific budget, an element or general (core) overheads will be recovered against those reserves. The percentage recovery date is a matter of judgement; however, costs allocated will be reasonable, proportionate, justifiable and transparent.

Unrestricted cash reserves should be not less than three months of unrestricted expenditure, based on the most recent three-months of unrestricted expenditure.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The Charity is governed by its Memorandum and Articles of Association and constitutes as a Charitable Incorporated Organisation.

Appointment of Trustees

Trustees are recruited as required to fill specific gaps and to complement the management experience of the Board of Trustees. Appointments are made in accordance with the Articles of Association, after the appointment has been approved by the resolution of Trustees.

Organisational structure

All policy, strategy and financial decisions relating to the Charity have to be formally approved by the Board of Directors. The Board meets six times a year on a bi-monthly basis. Three of these meetings are held at the charity's offices in Stratford upon Avon, alternating with meetings held by telephone conferencing.

Risk management

The Trustees have a duty to identify and review the risks to which the Charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees carried out regular reviews of the key risks affecting the Charity in the course of the year and took appropriate action.

Trustees

Dr H Sobati (appointed 21.11.24)
 Dr R Quinlivan (resigned 28.2.25)
 T J Mildon (resigned 25.3.25)
 M T Dearlove
 Mrs K M Jackson
 M P Collins (resigned 31.12.24)
 Ms L E J West
 Dr A M Emslie-Smith
 Dr A M Childs
 Mrs K Y Edwards
 J M Fiorentini (resigned 24.6.24)
 S Madipalli
 Mrs T J B Burnley
 B H Williams
 Mrs M M Aspinall
 Mrs J E Sheehan
 R S Hovey (resigned 31.12.24)
 D H W Worrall (appointed 21.11.24)

Auditors

Cooper Adams Ltd
 Chartered Accountants
 and Statutory Auditors
 12 Payton Street
 Stratford upon Avon
 Warwickshire
 CV37 6UA

Patrons

Professor V Dubowitz

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1106815

Principal address

Unit 9 Shottery Brook Office Park
 Timothy's Bridge Road
 Stratford upon Avon
 Warwickshire
 CV37 9NR

TRUSTEES' RESPONSIBILITY STATEMENT

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charity SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 11 July 2025 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'M T Dearlove'.

M T Dearlove - Trustee



REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES OF SPINAL MUSCULAR ATROPHY UK

Opinion

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charity') for the year ended 31 March 2025 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

- In our opinion the financial statements:
- Give a true and fair view of the state of the charity's affairs as at 31 March 2025 and of its incoming resources and application of resources, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- The information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- Sufficient accounting records have not been kept; or
- The financial statements are not in agreement with the accounting records and returns; or
- We have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in

accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

**David Cooper**

For and on behalf of Cooper Adams Ltd
Chartered Accountants
and Statutory Auditors
12 Payton Street
Stratford upon Avon
Warwickshire
CV37 6UA

11 July 2025



STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2025

		Unrestricted	Restricted	2025 Total	2024 Total
INCOME AND ENDOWMENTS FROM	Notes	funds £	funds £	funds £	funds £
Donations and legacies	2	708,423	899,925	1,608,348	1,253,639
Other trading activities	3	3,788	-	3,788	3,755
Investment income	4	11,409	-	11,409	6,459
Total		723,620	899,925	1,623,545	1,263,853
EXPENDITURE ON Raising funds	5	282,699	536	283,235	203,390
Charitable activities Provision of support	6	312,027	620,189	932,216	583,796
Governance costs		100,111	-	100,111	92,671
Research related activity		36,957	7,379	44,336	58,003
Total		731,794	628,104	1,359,898	937,860
NET INCOME/ (Expenditure)		(8,174)	271,821	263,647	325,993
Transfers between funds	16	(1,326)	1,326	-	-
Net movement in funds		(9,500)	273,147	263,647	325,993
RECONCILIATION OF FUNDS Total funds brought forward		595,560	386,747	982,307	656,314
TOTAL FUNDS CARRIED FORWARD		586,060	659,894	1,245,954	982,307

STATEMENT OF FINANCIAL POSITION

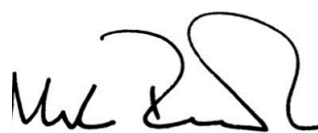
31 March 2025

	Notes	Unrestricted Funds £	Restricted Funds £	2025 Total Funds £	2024 Total Funds £
FIXED ASSETS					
Tangible Assets	11	7,914	-	7,914	8,762
CURRENT ASSETS					
Stocks	12	5,672	-	5,672	5,628
Debtors	13	30,364	30,850	61,214	25,598
Cash at bank and in hand		565,889	630,542	1,196,431	965,314
Total		601,925	661,392	1,263,317	996,540
CREDITORS					
Amounts falling due within one year	14	(23,779)	(1,498)	(25,277)	(22,995)
NET CURRENT ASSETS		578,146	659,894	1,238,040	973,545
TOTAL ASSETS LESS CURRENT LIABILITIES		586,060	659,894	1,245,954	982,307
NET ASSETS		586,060	659,894	1,245,954	982,307
FUNDS					
Unrestricted funds: General Fund				586,060	595,560
Restricted funds: Various Funds				659,894	386,747
TOTAL FUNDS				1,245,954	982,307

The financial statements were approved by the Board of Trustees and authorised for issue on 11 July 2025 and were signed on its behalf by:



K M Jackson - Trustee



M T Dearlove - Trustee

STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2025

	Notes	2025 £	2024 £
Cash flows from operating activities			
Cash generated from operations	1	223,509	336,003
Net cash provided by operating activities		223,509	336,003
Cash flows from investing activities			
Purchase of tangible fixed assets		(3,801)	(5,192)
Interest received		11,409	6,459
Net cash provided by/(used in) investing activities		7,608	1,267
Change in cash and cash equivalents in the reporting period		231,117	337,270
Cash and cash equivalents at the beginning of the reporting period		965,314	628,044
Cash and cash equivalents at the end of the reporting period		1,196,431	965,314

NOTES TO THE STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2025

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2025 £	2024 £
Net income for the reporting period (as per the Statement of Financial Activities)	263,647	325,993
Adjustments for:		
Depreciation charges	4,649	3,467
Interest received	(11,409)	(6,459)
Decrease in stocks	(44)	163
Decrease/(increase) in debtors	(35,616)	10,519
Increase/(decrease) in creditors	2,282	2,320
Net cash provided by operations	223,509	336,003

2. ANALYSIS OF CHANGES IN NET FUNDS

Net Cash	At 31.3.24 £	Cash flow £	At 31.3.25 £
Cash at bank and in hand	965,314	231,117	1,196,431
Total	965,314	231,117	1,196,431

NOTES TO THE FINANCIAL STATEMENTS

for the Year Ended 31 March 2025

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Office equipment	- 10 - 20% on cost
Computer equipment	- 25% straight line basis

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular purposes.

2. DONATIONS AND LEGACIES

	2025 £	2024 £
Donations and gifts	1,100,063	717,901
Legacies	149,250	159,944
Motability	239,000	238,500
The National Lottery Community Fund	120,035	137,294
	1,608,348	1,253,639

3. OTHER TRADING ACTIVITIES

	2025 £	2024 £
Merchandise Sales	3,788	3,755

4. INVESTMENT INCOME

	2025 £	2024 £
Bank Interest	11,409	6,459

5. RAISING FUNDS

Raising Donations and Legacies	2025 £	2024 £
Staff Costs	164,107	137,965
Fundraising and publicity	24,208	26,826
Events and promotions * * £35,381 (50% of total profit) was paid to the Wildlife Trust because the event was delivered in partnership with the Organisation.	90,820	33,953
Cost of merchandise sales	4,100	4,646
	283,235	203,390

6. CHARITABLE ACTIVITIES COSTS

Provision of Support	2025 £	2024 £
Staff Costs and other expenses	400,816	337,154
Information and awareness raising	30,904	19,722
Shared experience network	12,241	13,783
Outreach service	123,350	77,482
Welfare and equipment grants	364,905	135,655
	932,216	583,796

Research Related Activity	2025 £	2024 £
Staff costs and other expenses	30,277	42,412
Medical research grants	7,105	6,729
Other research activities	6,954	8,862
	44,336	58,003

7. SUPPORT COSTS

	Management £
Governance costs	100,111

	2025 £	2024 £
Staff costs and other expenses	80,303	75,039
Professional fees and bank charges	5,580	7,311
Other costs	14,228	10,321
	100,111	92,671

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2024.

Trustees' expenses

There were no trustees' expenses reimbursed for the year ended 31 March 2025 (2024: £nil).
Payments in respect of trustee indemnity insurance amounted to £678 (2024: £438).

9. STAFF COSTS

	2025 £	2024 £
Wages and salaries	545,504	483,714
Social Security costs	50,091	41,460
Pension	24,945	21,884
	620,540	547,058

The average monthly number of employees during the year was as follows:

	2025	2024
Management and administration	1	1
Direct charitable expenditure	10	12
Fundraising and publicity	5	5
	16	18

We also engaged contractors in 2025 to assist us with our management and administration 1.2 FTE.

No employees received emoluments in excess of £60,000 (2024:None)

10. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

INCOME AND ENDOWMENTS FROM	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Donations and legacies	624,113	629,526	1,253,639
Other trading activities	3,755	-	3,755
Investment income	6,459	-	6,459
Total	634,327	629,526	1,263,853
EXPENDITURE ON			
Raising funds	203,390	-	203,390
Charitable activities			
Provision of support	261,941	321,855	583,796
Governance costs	92,671	-	92,671
Research related activity	45,745	12,258	58,003
Total	603,747	334,113	937,860
NET INCOME	30,580	295,413	325,993
RECONCILIATION OF FUNDS			
Total funds brought forward	564,980	91,334	656,314
TOTAL FUNDS CARRIED FORWARD	595,560	386,747	982,307

11. TANGIBLE FIXED ASSETS

COST	Office equipment £	Computer equipment £	Totals £
At 1 April 2024	2,554	26,055	28,609
Additions	864	2,937	3,801
At 31 March 2025	3,418	28,992	32,410
DEPRECIATION			
At 1 April 2024	1,708	18,139	19,847
Charge for year	221	4,428	4,649
At 31 March 2025	1,929	22,567	24,496
NET BOOK VALUE			
At 31 March 2025	1,489	6,425	7,914
At 31 March 2024	846	7,916	8,762

12. STOCKS

	2025 £	2024 £
Stocks held for re-sale	5,672	5,628

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Prepayments and accrued income	61,214	25,598

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Taxation and social security	17,669	16,273
Other creditors	7,608	6,722
	25,277	22,995

15. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2025 £	2024 £
Within one year	7,500	15,000
Between one and five years	-	7,500
	7,500	22,500

16. MOVEMENT IN FUNDS

	At 31.3.24 £	Net movement in funds £	Transfers between funds £	At 31.3.25 £
Unrestricted funds				
General fund	595,560	(8,174)	(1,326)	586,060
Restricted funds				
Various funds	386,747	271,821	1,326	659,894
TOTAL FUNDS	982,307	263,647	-	1,245,954

16. MOVEMENT IN FUNDS – CONTINUED

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	723,620	(731,794)	(8,174)
Restricted funds			
Various funds	899,925	(628,104)	271,821
TOTAL FUNDS	1,623,545	(1,359,898)	263,647

Comparatives for movement in funds

	At 31.3.23 £	Net movement in funds £	At 31.3.24 £
Unrestricted funds			
General fund	564,980	30,580	595,560
Restricted funds			
Various funds	91,334	295,413	386,747
TOTAL FUNDS	656,314	325,993	982,307

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	634,327	(603,747)	30,580
Restricted funds			
Various funds	629,526	(334,113)	295,413
TOTAL FUNDS	1,263,853	(937,860)	325,993

16. MOVEMENT IN FUNDS – CONTINUED

A current year 12 months and prior year 12 months combined position is as follows:

	At 31.3.24 £	Net movement in funds £	Transfers between funds £	At 31.3.25 £
Unrestricted funds				
General fund	564,980	22,406	(1,326)	586,060
Restricted funds				
Various funds	91,334	567,234	1,326	659,894
TOTAL FUNDS	656,314	589,640	-	1,245,954

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	1,357,947	(1,335,541)	22,406
Restricted funds			
Various funds	1,529,451	(962,217)	567,234
TOTAL FUNDS	2,887,398	(2,297,758)	589,640

16. MOVEMENT IN FUNDS – CONTINUED Statement of funds	Balance b/f at 1.4.24 £	Incoming resources £	Resources expended £	Fund Transfers £	Balance c/f at 31.3.25 £
Unrestricted funds					
General fund	595,560	723,620	(731,794)	(1,326)	586,060
Restricted funds					
Equipment Grant	-	1,000	(1,000)	-	-
Flexible Response Grants	-	12,000	(12,000)	-	-
Community Information Webinars	5,000	-	-	-	5,000
Motability	127,861	239,000	(299,981)	-	66,880
SMA Care UK Grant	67,354	161,850	(40,653)	-	188,551
Community Engagement	47,350	9,500	(58,176)	1,326	-
Working with the SMA Community	61,504	120,035	(127,231)	-	54,308
Support Services	2,020	18,000	(20,020)	-	-
PhD Scholarship	3,270	10,000	(7,104)	-	6,166
SMA and Me Books	11,400	-	(10,215)	-	1,185
Know No Bounds	30,255	20,535	(29,384)	-	21,406
Content and Web Development	30,733	-	(6,065)	-	24,668
Edward Gostling	-	200,000	-	-	200,000
Adult Advocacy Workshops	-	20,396	(15,101)	-	5,295
The Big Weekend	-	57,707	(1,174)	-	56,533
Short Film NBS	-	29,902	-	-	29,902
Total Restricted Funds	386,747	899,925	(628,104)	-	659,894
TOTAL FUNDS	982,307	1,623,545	(1,359,898)	-	1,245,954

Analysis of net assets between funds

Fund balances at 31 March 2025 are represented by:	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Tangible fixed assets	7,914	-	7,914
Stock	5,672	-	5,672
Debtors	30,364	30,850	61,214
Bank and cash	565,889	630,542	1,196,431
Current liabilities	(23,779)	(1,498)	(25,277)
Total net assets	586,060	659,894	1,245,954

16. MOVEMENT IN FUNDS – CONTINUED

Flexible Response Grants

Our FlexiGrants support all those living with SMA. We have two grant schemes which are open to all. 1) To help with the costs of accessing NHS-funded treatment or assessment and 2) To assist with buying items that support independence and alleviate hardship

Community Information Webinars

We ask expert health, education and social care professionals questions on topics of interest and concern to the SMA Community such as on treatments, diet and exercise. These popular webinars hosted by a community member provide easy access to important up-to-date and accurate information.

Motability

SMA UK were awarded a 3 year grant from The Motability Foundation, giving us the opportunity to assist people living with SMA in purchasing mobility equipment and wheelchairs through our SMARt Moves grant.

SMA Care UK Grant

The SMA Care UK project will bring together members of the SMA community and a range of health care and other professions to update the guidance outlined in Standards of Care (2018) and ensure it is relevant and meaningful to those living with SMA in the UK today. Funding has been received and requested from trusts and industry.

Community Engagement

SMA UK received grants from trusts and pharma to support our community engagement events which included Picnics in the park and our Children's and adults resonate weekends.

Working with the SMA Community

This Fund goes towards the costs of our information, outreach and support, community development and advocacy services.

Support Services

This fund targeted any Support Services costs that were not covered by any of the other restricted funds that support this work.

PhD Scholarship

This supports our commitment to fund the 4-year research programme that aims to further understand the motor enlargement process in

people who have SMA and how this might be addressed and improve treatment outcomes. It runs from 2022–2025, and is funded jointly with Muscular Dystrophy UK.

SMA and Me Books

The books 'SMA and me' were published in 2016 before disease modifying treatments changed the landscape of SMA. With input from children living with SMA, their families and their clinicians, this new resource sponsored by Biogen, will help children to understand what SMA is, how the treatments work and, importantly, why we now see so many individual differences within the SMA community.

Know No Bounds

Two members of the SMA Community have set themselves a challenge to climb Snowdonia to fundraise for SMA UK to purchase specialist off road wheelchairs therefore aiming to give more opportunities for people living with SMA to explore the great outdoors.

Content and Web Development

As part of our on going website and communications development, we were awarded a grant to strengthen and facilitate Community engagement through our multimedia platforms whilst improving imagery including videos on the SMA UK website.

Edward Gosling

SMA UK benefited from a large legacy endowment from the Edward Gosling Foundation of £200k with the ability to draw down £40k per year for charitable activities.

Adult Advocacy Workshops

In January and February 2025, SMA UK held two insightful workshops in Manchester and London, bringing adults living with SMA and specialist clinicians together to discover the adult's perspectives of clinical care across the UK.

The Big Weekend

SMA UK's Big Weekend: Forty and Forward will be held in September 2025 bringing over 400 people from the SMA Community as well as clinicians and organisations with a special interest in SMA and disability.

Short Film NBS

Through an external grant received from Novartis and in partnership with Havas Life London, we have produced a short film highlighting the need for SMA to be added to the Newborn screening programme as fast as possible.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2025.

DETAILED STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2025

	2025 (£)	2024 (£)
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and gifts	1,100,063	717,901
Legacies	149,250	159,944
Motability	239,000	238,500
The National Lottery Community Fund	120,035	137,294
	1,608,348	1,253,639
Other trading activities		
Merchandise sales	3,788	3,755
Investment income		
Bank interest	11,409	6,459
Total incoming resources	1,623,545	1,263,853
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	164,107	137,965
Fundraising and publicity	24,208	26,826
Events and promotions	90,820	33,953
Cost of merchandise sales	4,100	4,646
	283,235	203,390
Charitable activities		
Staff costs and other expenses	431,091	379,565
Medical research grants	7,105	6,730
Other research activities	6,954	8,862
Information and awareness raising	30,905	19,722

Shared experiences network	12,242	13,783
Outreach service	123,349	77,482
Welfare, equipment grants and toy packs	364,906	135,655
	976,552	641,799

SUPPORT COSTS		
Management		
Staff costs and other expenses	80,303	75,039
Professional fees and bank charges	7,368	6,642
Other costs	12,440	10,990
	100,111	92,671
Total resources expended	1,359,898	937,860
Net income	263,647	325,993



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